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a focus group study of survivors' and professionals' experiences and preferences for rehabilitation care delivery

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Shared concern with current breast cancer rehabilitation services: a focus group study of survivors' and professionals' experiences and preferences for rehabilitation care delivery

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ABSTRACT

Objectives Breast cancer survivors experience a wide spectrum of physical sequelae from cancer treatment. National and international guidelines recommend that rehabilitation is offered from the point of diagnosis. However, there is a lack of data on the translation of these recommendations into clinical care. The objective of this study was to explore the experiences of breast cancer survivors, rehabilitation professionals and breast surgeons on current rehabilitation services including preferences for care delivery, specific ways to promote early detection and timely management of upper body issues and attitudes towards self-managed surveillance and rehabilitation.

Design Qualitative focus groups. Breast cancer survivors completed a questionnaire about rehabilitation services received and experience of upper body issues. These quantitative data were collected to provide context for the qualitative data and increase transferability. Transcripts were analysed using content analysis.

Setting Five geographically distinct health authorities in British Columbia, Canada.

Participants Eleven focus groups were conducted with 35 breast cancer survivors, 29 rehabilitation professionals and 5 breast surgeons.

Results Three categories captured participants' concern and wish for improved care: (1) *cut the cancer out and goodbye*; (2) *you have to look out for yourself* and (3) *in a perfect world*. All breast cancer survivors reported chronic upper body issues (mean 4.5 unique issues). Breast cancer survivors expressed worry and uncertainty in their solo management of the rehabilitation. The current services were reported to not enable early detection and timely management. Suggestions included reorganising the timing of patient education and improving the quality of and access to rehabilitation services by elevating the knowledge among healthcare professionals and providing multimodal self-management resources.

Conclusions The results revealed a gap between oncology guidelines and the current clinical reality. The rehabilitation services were reported in need of revamping to increase equity of care. Multiple upper body issues were reported by many breast cancer survivors.

Strengths and limitations of this study

- This is the first study, to our knowledge, to provide insight into the translation of breast cancer rehabilitation guidelines into clinical rehabilitation programmes in Canada.
- A diverse range of health professionals from primary and secondary settings and survivors from across the five geographically different health authorities in the British Columbia, Canada, were sampled.
- In-depth focus groups were conducted, and data were analysed using robust qualitative methodology including researcher and data triangulation.
- All participants had recent experience with rehabilitation services and were sampled to maximise variation in important demographics.
- Those health professionals and survivors with stronger views on the current rehabilitation services may have been more inclined to participate in the study.

INTRODUCTION

Rehabilitation is recommended to help cancer survivors regain functional independence and to mitigate subsequent disability.[1] While national and international cancer guidelines recommend that rehabilitation is offered from the point of diagnosis, rehabilitation services are often not integrated into cancer care services. Breast cancer survivors (BCSs) experience a wide spectrum of physical sequelae from cancer treatment, such as upper body pain and tightness, limited shoulder range of motion (ROM), reduced upper body muscle strength and function[2] and breast cancer-related lymphoedema

(BCRL),[3] together referred to as upper body issues. To mitigate the development of these issues, clinical guidelines recommend that BCSs begin an early postsurgery upper body rehabilitation exercise programme.[4 5] Furthermore, recommendations from experts in the field are to have presurgery measurements taken of arm circumference and shoulder ROM[6 7] to serve as baseline measures and to use for early detection of upper body issues. However, there is a lack of data on the translation of these recommendations into clinical care.

Oncology rehabilitation programmes are scarce in Canada and are predominantly delivered in hospitals located in larger cities.[8] In addition, Canadian healthcare professionals report that existing programmes do not meet the rehabilitation needs of their patients with the main barriers being: (1) access to care; and (2) availability of space and staffing.[8] The shortfall between the rehabilitation capacity and the prevalence of breast cancer means that only a minority of BCSs have access to oncology rehabilitation.

To understand the needs and barriers for providing quality rehabilitation, an in-depth exploration of the experiences of BCSs and healthcare professionals on current rehabilitation care delivery is needed. Furthermore, the specific preferences with respect to upper body rehabilitation programming have yet to be thoroughly explored but are crucial considerations in ensuring the feasibility and acceptability of future rehabilitation programmes for this population. The aim of the current study was therefore to explore the experiences among BCSs, rehabilitation professionals (RPs) and surgeons on current rehabilitation services within the public setting. We also sought preferences for rehabilitation care delivery including how to promote early detection and timely management of upper body issues and explored the attitudes towards self-managed surveillance and rehabilitation.

MATERIALS AND METHODS

Design

Focus groups along with questionnaires was chosen to allow data source triangulation,[9] to understand BCSs' experiences as well as to quantify the rehabilitation received. This allowed us to explore and compare the experiences and preferences from participants at different sites and among different target groups.[10] The study is reported consistently with the consolidated criteria for reporting qualitative studies checklist.[11]

Participants and procedures

In British Columbia, a province within Canada, healthcare is delivered through five geographically based health authorities (HAs). Purposive sampling was used to obtain perspectives from three target groups: (1) BCSs; (2) RPs (primarily physical therapists and selected nurses and lymphoedema therapists) working in rehabilitation of BCSs; and (3) breast surgeons (BSs). We aimed to recruit approximately 30 BCSs, 20 RPs and 5 BSs. We considered this sample size would provide richness and density of data to meet the study aims. In each of the five HAs, we conducted one focus group with BCSs and one with RPs. A focus group with BSs was conducted in one HA.

Recruitment efforts included bulletins with study information posted at hospitals across British Columbia and word of mouth. Lastly, BCSs who had participated in our previous studies were emailed with study information and invited to participate. Maximal variation was sought for BCSs in area of residence, age, income and education. As such, it was not sought to recruit a representative sample but rather a sample with varied experiences and perspectives. A snowball sampling strategy was applied for RPs and BSs. RPs working with oncology rehabilitation at the larger hospitals in each HA were invited to participate and asked to identify colleagues who manage rehabilitation for BCSs. In addition, RPs from private practices with specialty in breast health were identified from the Physiotherapy Association of British Columbia website and invited via email to participate. The BSs were recruited through word of mouth. The first author contacted all potential participants via telephone or email to confirm interest and eligibility, as well as to schedule the focus group.

Eligibility criteria for BCSs were: (1) ≥18 years; (2) currently undergoing or within 5 years of primary treatment for any stage breast cancer; and (3) being able to understand and speak English. Eligibility criteria for RPs were: (1) licenced physical therapist, nurse or lymphoedema therapist; (2) having ≥1 year of clinical experience that included care of BCSs; and (3) being able to understand and speak English. Eligibility criteria for BSs were: (1) practising BS; (2) having ≥1 year of clinical experience that included care of BCSs; and (3) being able to understand and speak English.

Research team and reflexivity

JM, PC and KLC are experienced in qualitative research and supervised BSR during this study. BSR was a PhD candidate with experience in breast cancer rehabilitation research. JM is an associate professor and very experienced qualitative researcher. PC is a clinician-scientist with experience in conducting focus groups across British Columbia. KLC is an associate professor with extensive experience with breast cancer rehabilitation research. The team assumed that participants living in the metropolitan areas would report more positive experiences with and greater access to rehabilitation services than participants living in rural areas.

Patient and public involvement

Two patient representatives and one healthcare representative were involved in developing the interview guide. Preliminary results were reported to participants via a webinar to allow for feedback and validation of the analysis. Finally, a third patient representative participated in the dissemination of the results to the funding agency.

Data collection and analysis

Written informed consent was obtained from all participants. Prior to the focus group discussions, BCSs completed sociodemographic, medical and rehabilitation services and needs questionnaires (online supplementary file 1). RPs and BSs completed a questionnaire about setting of work and years of experience. All questionnaires were developed for the study specifically, and results were reported descriptively as number and proportions of participants who i.e., reported to have received education about rehabilitation. The quantitative data were collected to provide as much context as possible for the qualitative data and thereby increase transferability. Following completion of questionnaires, participants took part in a semistructured focus group that took place at meeting rooms in hospitals in each of the HAs and were held between September and December 2017. Participant local travel costs were reimbursed, but no payment was provided for participation. The first author conducted all focus groups using a guide with open-ended questions developed based on the research aim (online supplementary file 2). These questions focused on participants' perspectives on current rehabilitation services, beliefs and attitudes towards self-management strategies for upper body issues, and ideas and preferences towards modes of delivery for rehabilitation services. Participants were not informed about the researchers' prior research or specific interests. Field notes were not used. Volunteers were present to support the collection of questionnaires.

Group discussions were audio and video recorded, transcribed verbatim, anonymised and analysed using content analysis[12] and researcher triangulation.[9] As preparation, the overall sense of the data was identified from a preliminary review of the transcripts (BSR and JM). NVivo V.12 software (QSR International, Melbourne, Australia) was then used to organise the raw data through open coding by one researcher (BSR) during repeated readings of the transcripts. In the next step, the data were grouped, and the number of categories were reduced by combining similar headings into broader categories with additional categories interpreted deductively.[13] These categories were sorted according to predefined topics from the focus group guide to address the study aims. Subcategories were refined, and final categories were named using empirically derived words and organised under one overarching category.

RESULTS

The sample consisted of 35 BCSs, 29 RPs and 5 BSs. BCSs had a mean age of 54.2 (min: 34; max: 78) years and were a mean of 1.9 (SD 2.9) years after primary surgery for breast cancer (table 1). RPs represented 18 clinical sites with a mean of 9.1 (SD 7.4) years of experience with cancer rehabilitation. BSs had a mean of 21.6 (SD 10.4) years of experience, and each performed an average of 191.0 (SD 146.3) surgeries for breast cancer per year. The 11 focus groups ranged from 46 to 78 min, with a mean length of

Table 1 Participant characteristics

Women with breast cancer	n=35
Age, mean (SD)	54.2 (10.2)
Min–max	34–78
Ethnicity, n (%)	
Caucasian	28 (80.0)
Asian	4 (11.4)
Other	3 (8.6)
Region of residence, n (%)	
North	8 (22.9)
Vancouver Island	9 (25.7)
Interior	6 (17.1)
Fraser	4 (11.4)
Vancouver	8 (22.9)
City population, n (%)	
Metropolis >500 000	6 (17.1)
Urban 50 000–500 000	23 (65.7)
Town <50 000	6 (17.1)
Marital status, n (%)	
Married	17 (48.6)
Common law	3 (8.6)
Separated	3 (8.6)
Widowed	1 (2.9)
Divorced	5 (14.3)
Never married	6 (17.1)
Education, n (%)	
Some high school	1 (2.9)
Completed high school	2 (5.7)
Some university/college	8 (22.9)
Completed university/college	15 (42.9)
Some graduate school	2 (5.7)
Completed graduate school	7 (20.0)
Family income in $C, n (%)	
<20 000	2 (5.7)
20 000–39 999	5 (14.3)
40 000–59 999	4 (11.4)
60 000–79 999	3 (8.6)
80 000–99 999	6 (17.1)
>100 000	15 (42.9)
Employment status, n (%)	
Disability	6 (17.1)
Retired	8 (22.9)
Part-time	7 (20.0)
Full-time	13 (37.1)
Temporarily unemployed	1 (2.9)
Smoking status, n (%)	
Never smoked	20 (57.1)

Continued

Table 1 Continued

Ex-smoker	12 (34.3)
Occasional smoker	1 (2.9)
Regular smoker (smoke every day)	2 (5.7)
Living arrangement, n (%)	
Live with spouse/other family member	25 (71.4)
Live alone	10 (28.6)
Breast cancer stage, n (%)	
0	2 (5.7)
I	2 (5.7)
II	8 (22.9)
III	7 (20.0)
IV	2 (5.7)
Unknown	14 (40.0)
Recurrence/second breast cancer, n (%)	6 (17.1)
Breast cancer surgery, n (%)	
Mastectomy	26 (74.3)
Lumpectomy	9 (25.7)
Reconstructive surgery, n (%)	
No	16 (45.7)
Implant	11 (31.4)
TRAM flap	2 (5.7)
NA	6 (17.1)
Lymph node dissection, n (%)	
Axillary lymph node dissection	17 (48.6)
Sentinel lymph node dissection	16 (45.7)
Neither /unknown	2 (5.7)
Number of lymph nodes removed, mean (SD)	9.66 (7.84)
Number of positive lymph nodes, mean (SD)	2.23 (3.12)
Postsurgical complications, n (%)	
Infection	4 (11.4)
Drainage issues	7 (20.0)
Seroma	8 (22.9)
Haematoma	0 (0)
Adjuvant therapy, n (%)	
Chemotherapy	23 (65.7)
Radiation therapy	25 (71.4)
Time since surgery, years, mean (SD)	1.9 (2.9)
Rehabilitation professionals	n=29
Age, mean (SD)	45.0 (10.7)
Min–max	26–65
Highest degree attained, n (%)	
Physical therapist (BSc)	18 (62.1)
Physical therapist (MSc)	7 (24.1)
Lymphoedema therapist	2 (6.9)
Registered nurse	2 (6.9)
Breast cancer continuing education, n (%)	17 (58.6)

Continued

Table 1 Continued

Region of residence in British Columbia, n (%)	
North	6 (21)
Vancouver Island	6 (21)
Interior	7 (24)
Fraser	6 (21)
Vancouver	4 (14)
Primary practice setting, n (%)	
Hospital-based outpatient	11 (37.9)
Inpatient acute care	10 (34.5)
Private practice	8 (27.6)
Settings represented, n	18
Hospitals	10
Private clinics	8
Years worked as RP, mean (SD)	18.9 (10.3)
Min–max	1–40
Years worked in oncology rehabilitation, mean (SD)	9.1 (7.4)
Min–max	1–25
Hours/week in patient care, mean (SD)	30.1 (9.4)
Min–max	10–40
Cancer-related patients/week, mean (SD)	6.4 (8.7)
Min–max	0–30
Percentage of hours/week involving cancer-related conditions, mean SD)	20.1 (28.7)
Min–max	0–100
Time point to deliver treatment*, n (%)	
Presurgery	7 (24.1)
Within first month of surgery	16 (55.2)
Within 6 months of surgery	15 (51.7)
6–12 months postsurgery	13 (44.8)
>12 months postsurgery	7 (24.1)
Breast surgeons	n=5
Years of experience, mean (SD)	21.6 (10.4)
Breast cancer surgeries/year, mean (SD)	191.0 (146.3)

*RPs could choose more than one answer, so % is above 100%.
NA, not applicable; RP, rehabilitation professional; TRAM, transverse rectus abdominis.

66 min. Three BCSs and one RP had participated in prior research and thus knew BSR. An additional 14 BCSs, 11 RPs and two BSs were interested but unable to participate primarily due to scheduling difficulties and were not included. Data saturation was obtained as similar experiences and perspectives were raised at the fourth and fifth focus group with BCSs and RPS, and consequently no new codes or themes were identified during the data analysis.[14]

Specific to BCSs experience with rehabilitation, presurgery measurements were reported by two (6%) and by

six (17%) BCSs for shoulder ROM and arm circumference, respectively (table 2). Seven (20%) BCSs reported never receiving education about upper body rehabilitation. Nine (26%) BCSs reported being referred to rehabilitation by a healthcare professional, while 14 (40%) reported self-referring to rehabilitation and 12 (34%) reported not receiving any rehabilitation. Five (14%) BCSs reported experiencing upper body issues prior to surgery, while 35 (100%) reported currently experiencing upper body issues. From the qualitative data with all three groups, the overarching category identified was *United in concern and wish for improved care*, which reflected participants' shared concern with the public system where BCSs were ill equipped to manage upper body issues, and the unifying wish to improve rehabilitation care. Moreover, three main categories, each with subcategories, were identified: (1) *cut the cancer out and goodbye*; (2) *you have to look out for yourself;* and (3) *in the perfect world* (figure 1). The following section presents a description of each category with selected illustrative quotes. Quotes are for example coded as 'BCS, HA3, P2', corresponding to a BCS from HA #3 who was participant #2 in the focus group.

Cut the cancer out and goodbye

This category offers an understanding of the experiences of and perspectives on the public rehabilitation services. BCSs and RPs discussed how cancer treatment (surgery and adjuvant therapies) and rehabilitation (education, self-management resources and referral to physical therapy) were disconnected. BCSs experienced the time of surgery as being in a 'revolving door'"with a short stay at the hospital without priority of education about rehabilitation. Specifically, BCSs strongly emphasised a lack of education about how to identify and manage upper body issues and a lack of referral to physical therapy. BSs and RPs working in public settings expressed concern with the limited services provided. Additional quotes for this category are listed in online supplementary table 1.

No or insufficient patient education

BCSs discussed emotionally that they had received little education about how to manage upper body issues. They felt that the medical team was focused on removing the tumour, while little emphasis was put towards the consequences of surgery. Most BCSs had received education about rehabilitation only once in the form of a pamphlet with postsurgical upper body exercises. BCSs and RPs shared that the verbal education often was delivered quickly when the survivor had just undergone surgery, was on pain medication and unable to retain the information.

> They say after you've had a surgery not to sign any documents for at least 24 hours. So, let's not tell patients important information. Like how dare you come in when I'm half corked out of my tree and lay all this information on me and now I'm responsible for it?! (BCS, HA2, P4)

Table 2 Rehabilitation services and needs among breast cancer survivors

Presurgery measurement, n (%)	
Shoulder ROM	2 (5.7)
Performed by	
Self-measured	1 (2.9)
Physical therapist	1 (2.9)
Arm circumference	6 (17.1)
Performed by	
Self-measured	2 (5.7)
Physical therapist	2 (5.7)
Nurse	2 (5.7)
When was rehabilitation education received*, n (%)	
Never	7 (20.0)
Presurgery	15 (42.9)
Within first month postsurgery	8 (22.9)
Later	8 (22.9)
Who delivered rehabilitation education*, n (%)	
No one	7 (20.0)
Physical therapist	13 (37.1)
Surgeon/oncologist	6 (17.1)
Chiropractor	1 (2.9)
Other (massage therapist and nurse)	15 (42.9)
Referred to physical therapy, n (%)	
By healthcare professional	9 (25.7)
Self-referred	14 (40.0)
Not referred	12 (34.3)
Reason for referral*, n (%)	
Shoulder ROM	17 (48.6)
Upper body muscle strength	10 (28.6)
Lymphoedema	12 (34.3)
Scar tissue	5 (14.3)
Cording	1 (2.9)
Peripheral neuropathy	1 (2.9)
General exercise	7 (20.0)
Setting of rehabilitation care, n (%)	
Private practice	9 (25.7)
Public facility	7 (20.0)
Combination of private and public	4 (11.4)
Alternative or complementary treatment†, n (%)	23 (65.7)
Self-managed upper body issues, n (%)	
During treatment	32 (91.4)
After treatment	32 (91.4)
Sufficient support to self-manage upper body issues	18 (51.4)
Upper body issues, n (%)	
Prior to surgery	5 (14.3)

Continued

Table 2 Continued

Currently	35 (100.0)
Number of upper body issues, mean (min-max)	mean=4.5, min=1, max=9
Current upper body issues, n (%)	
Tightness	33 (94.3)
Numbness	23 (65.7)
Muscle strength	20 (57.1)
Shoulder ROM	18 (51.4)
Pain	16 (45.7)
Skin changes (fibrosis/scarring)	15 (42.9)
Lymphoedema	14 (40.0)
Cording	10 (28.6)
ADL limitations	7 (20.0)
Skin infection/cellulitis	1 (2.9)

*Participants could choose more than one answer, so % is above 100%.
†Examples of alternative/complementary treatment: massage therapy, diet, mindfulness, manual lymph drainage, yoga and meditation.
ADL, activities of daily living; ROM, range of motion.

Lack of (awareness of) public rehabilitation services

Rehabilitation services were consistently reported to be lacking. The BSs shared that options for referral to public facilities were limited, especially for BCSs living outside the metropolitan area, which hindered or delayed rehabilitation treatment.

> I was never made aware of, never offered, never signed up for or referred to any kind of rehab. (BCS, HA3, P2)

Insufficient training of healthcare professionals

Awareness of the importance of rehabilitation as well as expertise in delivering oncology rehabilitation among some healthcare professionals was expressed by the BCSs to be limited. Lack of recognition of upper body issues often prohibited referral into the public rehabilitation services. Furthermore, some PTs in public settings were perceived to lack education into oncology rehabilitation.

> I don't think we can educate patients until we educate the people who are looking after the patient. I think the therapist and the nurses know exactly what's going on, but the problem is the patient is going to the doctor, they're going to their family doctor, their surgeon, their oncologist and when they blow that off and say, 'oh you're fine', that has a huge weight. I think we have to back up and look at that. (RP, HA1, P1)

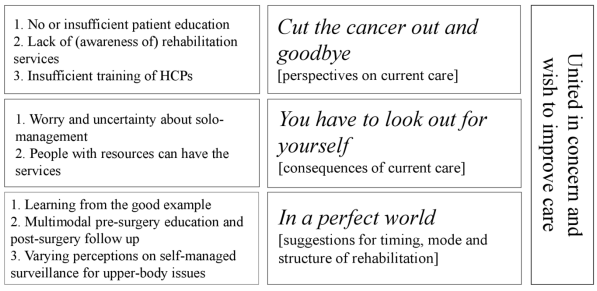

Figure 1 Coding tree with categories and subcategories. HCPs, healthcare professionals.

You have to look out for yourself

This category offers an understanding of the consequences of the current public rehabilitation services. BCSs described worry and uncertainty when self-managing upper body issues, disparities in access to existing rehabilitation services and consequently delayed start of treatment when issues were difficult to manage. The 'lucky' BCSs who have the resources to be their own advocates and pay for treatment by specialised RPs escape into the private settings. Both BCSs, RPs and BSs express concern with those less fortunate. Additional quotes for this category are listed in online supplementary table 2.

Worry and uncertainty about solo management

The insufficient education left the BCSs worried and unsure if the rehabilitation exercises were helpful or harmful and ill equipped to identify issues and seek appropriate care. Furthermore, the BCSs reported that they were in a situation of solo management, where they solely were responsible for managing the rehabilitation due to the lack of public rehabilitation services.

> Is it tight because I should be working on it or is it tight because I shouldn't be doing this? That's what you're always worried about, am I going to make it worse. (BCS, HA4, P2)

People with resources can have the services

RPs viewed the system to be 'two-tiered', where BCSs with resources (ie, personal initiative, ability to ask questions and seek information, support from social community, financial resources or extended health insurance to pay for treatment in private settings) can access services while BCSs without those resources receive no or delayed treatment. Furthermore, a concern with the 'unethical' system with inequity of rehabilitation care was expressed which was viewed to hinder timely treatment especially for patients with fewer resources.

> It's a two-tiered system. If people have money I can send them off to private practice to some very, very experienced people. But if they have no money, that is a major problem. (RP, HA1, P1)

BCSs with resources spoke about their 'way out of the system' specifically, the barriers associated with identifying

specialised RPs and paying for the service, and feeling sense of privilege and at the same time deep concern about what other (less fortunate) women do. One BS shared how she sometimes must work around the system to address the inequity of care. RPs highlighted the lack of emphasis on prevention and the need for early identification of complications. The lack of early identification and subsequent delayed start of treatment often led to the development of chronic upper body issues (eg, irreversible BCRL).

In a perfect world

This category offers ideas and suggestions for improving patient education and access to rehabilitation services. This includes suggestions for timing, mode and structure of patient education and follow-up supported by multimodal self-management resources. Additional quotes for this category are listed in online supplementary table 3.

The good example

One hospital had a rehabilitation programme that included a presurgery education class for all BCSs (information about BCRL, instruction in the rehabilitation exercises, provision of a pamphlet to support self-managed rehabilitation and measurements of shoulder ROM and arm circumference) and planned follow-up appointments (repeated measurements to enable detection of upper body issues). The RPs working at this hospital considered their patients to be fortunate, and the BCSs who had received care here were satisfied with the programme.

> I was very impressed with the way they have it set up here. If this could exist everywhere, that would be ideal. (BCS, HA5, P2)

Multimodal presurgery education and postsurgery follow-up

RPs emphasised the importance of early detection and management of upper body issues and discussed ways to facilitate this. A different timing of patient education was needed, and a presurgery session was considered to be ideal to allow RPs to 'plant the seed' about the importance of rehabilitation. Benefits of having a dialogue (instead of written material only) was highlighted. Another benefit was the opportunity to initiate rehabilitation exercise before surgery for those with pre-existing upper body issues.

RPs discussed different modes of delivery of patient education, including a video-conference or a video guide, for sites where scheduling difficulties (ie, few surgeries or long commute for patients) would prohibit a group class. In addition, the importance of presurgery measurement of arm circumference was discussed including ways to include such assessments without adding extra visits for the patient.

> A pre-op class would be the perfect scenario, because you could hit the highlights in the book and get them to do the exercises when they're well so they know what to do. It's about planting the seed. (RP, HA3, P3)

Similarly, ways of facilitating distance-based follow-up at set intervals were discussed to support self-management and screen patients to provide services to those in greater need. While face-to-face appointments were viewed to be ideal, distance-based follow-up was considered to be beneficial for screening for upper body issues.

Varying perceptions on self-managed surveillance for upper body issues

Some BCSs noted that it would be hard to do self-measurement of arm circumference and shoulder ROM, while most thought that it would be great to track own recovery. Some RPs viewed a self-assessment tool to be beneficial and be more likely to happen than therapist-led surveillance.

> I think that a self-assessment tool, whether it's through an app or a video, if it's followed up with person contact can be really beneficial. (RP, HA1, P5)

In contrast, BSs were concerned about introducing self-managed surveillance and worried it would be difficult for patients and evoke anxiety.

> I think it would be difficult for patients to do arm measurements with the tape measure. (BS, HA3, P1)

DISCUSSION

Across the three groups, participants shared concern with the public system where BCSs were ill equipped to manage upper body issues and a unifying wish to improve rehabilitation care. Participants' accounts revealed that patient education is important, and a lack of education does not provide BCSs with the skills and confidence to undertake effective self-management. Furthermore, when awareness of available rehabilitation services is limited, then treatment is often initiated only when upper body issues are difficult or impossible to resolve. All BCSs in this study experienced chronic upper body issues that point to the consequences of the identified drawbacks with the current care. Participants indicated that even within a healthcare system that strives to have one-tier quality care, the current system is in fact two tiered. Participants described a need for presurgery education and postsurgery follow-up, provision of multimodal self-management resources and improved awareness of existing public and private oncology rehabilitation facilities. To develop effective rehabilitation programming to address the high prevalence of chronic upper body issues in this population, these factors must be addressed.

Based on our findings, cancer treatment is still perceived to focus only on diagnosis, treatment and symptom alleviation, while rehabilitation of functional and physical problems are under-recognised and undertreated.[15] This is a paradox because physical disability including upper

body issues is often a leading cause of distress among BCSs.[16 17] In our study, 20% of BCSs reported receiving no information on rehabilitation exercises, 34% had never seen an RP for treatment or education and only a minority had presurgery measurements taken of shoulder ROM and arm circumference. This is not in concordance with the national and provincial recommendations.[4 6] Thus, the timing and quality of care must be improved to meet the recommendations. In addition to physical therapists, practitioners of rehabilitation medicine or physiatrists are the uniquely qualified to serve this need and fill the gap. The fact that there are so few physiatrists likely contribute to the issue in getting the patients the care they require. This gap between recommendations and clinical practice highlights the need to consider other strategies, such as self-management programmes, to increase the reach and access of evidence-based rehabilitation. To begin to address this, we have developed freely available self-management upper body rehabilitation[18 19] and surveillance[20 21] resources and demonstrated them to be feasible and acceptable to include in public settings[18 22] and able to support BCSs in performing measurements for upper body issues on themselves in a reliable and valid manner.[20 22] Future research will establish if integrating such self-management resources into clinical programmes can enable early detection and management and lower the prevalence[23–25] and complexity[26] of upper body issues as demonstrated by therapist-administered surveillance programmes.

Participants described inequity of access to rehabilitation and concern for patients unable to be their own advocates. This echoes existing research indicating that disparities in access to rehabilitation cause underutilisation of existing services[27] and development of chronic upper body issues among BCSs, especially for patients with low income.[28 29] One of the many determinants of inequalities in health concerns utilisation of existing health services.[30] Bourdieu's capital-based approach[31] with its economic (eg, money and financial assets), cultural (eg, education, experience and communication competences) and social capital (eg, connections and network) can serve to understand the determinants of inequalities in the use of health services.[32] A scoping review demonstrated a direct correlation between an increase of vulnerability factors (ie, lack of health insurance, low level of education and low financial resources) and the escalation of healthcare disparities.[33] Thus, vulnerable BCSs with low cultural or social capital with inability to request referral to rehabilitation treatment may not be aware of nor use the existing services. While Canada has publicly funded healthcare, the marked shortfall of public oncology rehabilitation programmes[8 34] is a major contributor to the described inequality of care. In other countries of universal healthcare, the utilisation of supportive care (ie, physical therapy) by survivors is quite equitable and explained by patient-perceived need (ie, lower physical or mental health) and clinical factors (tumour stage and adjuvant therapies).[35] Lack of knowledge about the benefits of oncology rehabilitation among patients and referring clinicians may further aggravate the underuse of existing services.[27] The participating BCSs and RPs expressed a need to educate referring clinicians to improve their ability to identify patients in need for rehabilitation. Oncologists are often not successful in identifying supportive care needs among patients nor referring to relevant services.[36–38] As a result, a negligible number of survivors access physical therapy or other oncology rehabilitation services, with lowest utilisation among survivors of low education.[38] Together, this underscores the need for educating referring clinicians and RPs and underpins the importance of educating and providing resources for survivors to self-identify and self-manage issues confidently and effectively.

Participants shared ideas for ways to improve the public rehabilitation services. Simple initiatives such as reorganising the timing of services by providing patient education before surgery instead of the day of surgery could have substantial impact on patients' ability to retain the information. Furthermore, this could potentially alleviate the worry and uncertainty currently experienced by BCSs and support them better in managing the rehabilitation. In line with this, a recent trial demonstrated that face-to-face preoperative physiotherapy education and training prior to upper abdominal surgery improve participants' ability to remember the information[39] and halves the number of postoperative complications[40] compared with receiving a booklet only.

The strengths of this study stem from the combination of data from focus groups and questionnaires from three distinct groups. This approach allowed us to quantify the rehabilitation services and needs as well as understand the perspectives and consequences of the services among the groups. The group discussions were successful in engaging participants and likely revealed richer and clarified data compared with individual interviews. While the external validity is good given the sampling strategy and wide inclusion criteria, the possibility of self-selection bias cannot be ruled out as those with more positive or negative experiences or those who are uncomfortable to engage in group discussions may not have chosen to participate. Furthermore, we were able to conduct a focus group with BSs in only one HA and thereby did not capture the experiences and preferences of BSs in the other HAs. Lastly, the suggestions towards delivery of rehabilitation care to improve access should be further investigated and refined to guide the selection and tailoring of programme elements that will maximise uptake, acceptability and likelihood of implementation.

CONCLUSION

This study revealed that the current rehabilitation services need revamping to give BCSs greater confidence for self-management and to increase the equity of care. Participants highlighted a need for reorganising the timing of patient education and improving the quality of and access

to rehabilitation services by elevating the knowledge among healthcare professionals and providing multimodal self-management resources. Future programming must address these concerns and acknowledge that partnership is needed to connect care for cancer survivors.

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